Arolygiaeth Gofal Iechyd Cymru
Healthcare Inspectorate Wales

Health and Social Care Committee

Inquiry into residential care for older people

RC68 – Healthcare Inspectorate Wales and the Care and Social Services Inspectorate Wales

Mark Drakeford AM
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Eich cyf / Your ref:
Ein cyf / Our ref:

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Dear Mr Drakeford

Inquiry into Residential Care for Older People

Thank you for inviting Healthcare Inspectorate Wales (HIW) and the Care and Social Services Inspectorate Wales (CSSIW) to submit evidence to the Committee's inquiry into residential care for older people.

HIW's work in relation to healthcare services in Wales and CSSIW in relation to social care brings us into contact with older people who are in residential care, or may be on a pathway of care that could lead to a move into a residential care establishment.

Specifically, we would like to draw the Committee's attention to *Growing old my way: A review of the Impact of the National Service Framework (NSF) for Older People in Wales, the* report of a joint HIW/CSSIW review which is due to be published in early January 2012. We will ensure a copy is sent to the Committee when it is published.

In our review we looked at seven of the ten standards established in the National Service Framework for Older People in Wales using the pathway of an individual with dementia; to enable us to provide an answer to a key question - '***What impact is the NSF having on the quality of life of older people in Wales?'*** As part of the review we looked at how health and social care organisations support "health promotion, well-being and prevention" and "the maintaining independence at home for as long as possible". A summary of our findings is set out in our attached evidence paper.

We, or appropriate representatives from HIW/CSSIW, would be willing to attend the Committee to give evidence in person. It may be helpful for HIW and CSSIW to attend together, so that we can present the relevant findings of our joint report.

Yours sincerely

Dr Peter Higson
Chief Executive, HIW

Imelda Richardson
Chief Inspector, CSSIW

Health and Social Care Committee
Committee Inquiry into Residential Care for Older People in Wales

Healthcare Inspectorate Wales and Care and Social Services Inspectorate Wales Evidence Paper

Purpose

Healthcare Inspectorate Wales (HIW) and the Care and Social Services Inspectorate Wales (CSSIW) have been invited to submit written evidence to the Committee in relation to the “Inquiry into Residential Care for Older People in Wales”.

HIW and CSSIW welcome the Committee’s inquiry and the opportunity to provide written evidence. We would be prepared to supplement our written evidence with oral evidence at Committee should we be called to do so.

Background

The role of HIW

HIW is the independent inspectorate and regulator of all healthcare in Wales. HIW’s primary focus is on:

- Making a significant contribution to improving the safety and quality of healthcare services in Wales.
- Improving citizens’ experience of healthcare in Wales whether as a patient, service user, carer, relative or employee.
- Strengthening the voice of patients and the public in the way health services are reviewed.
- Ensuring that timely, useful, accessible and relevant information about the safety and quality of healthcare in Wales is made available to all.

HIW’s core responsibility is to provide independent assurance about the quality and safety of NHS and independent healthcare organisations in Wales against a range of standards, policies, guidance and regulations and to highlight areas requiring improvement. HIW also undertakes special reviews where there may be systemic failures in delivering healthcare services to ensure that improvement and learning takes place.

The role of CSSIW

The role of the Care and Social Services Inspectorate for Wales (CSSIW) is to encourage the improvement of social care, early years and social services by regulating, inspecting and reviewing services. We provide professional advice on care and social services issues to Welsh Ministers and policy makers. Our aim is to raise standards, improve quality, promote best practice and tell people about social care.

Our work covers the whole of Wales. We review services at both a national and local level so we can tell the public whether services are up to standard; suggest ways of improving services, and help safeguard the interests of service users and their carers. We inspect and review the performance of local authorities on specific topics. We regulate and inspect services for everyone from the very young to older people. Our work can affect the lives of the majority of people living in Wales at some time in their lives.

Key Findings from a joint review by HIW and CSSIW - Growing old my way: A review of the Impact of the National Service Framework (NSF) for Older People in Wales

Background

Our review focussed on the question: '*What impact is the NSF having on the quality of life of older people in Wales?'*

Over a period of two years HIW and CSSIW worked together to gather, assess and evaluate available information. A key aspect of this review was the gathering of the views of service users and their families and so Age Alliance Wales (AAW) was commissioned to facilitate service user and carers events across Wales. The work undertaken in support of this review also involved a number of other work streams including stakeholder events, unannounced hospital visits and the issue of GP questionnaires.

One major concern highlighted very early on in the planning and scoping of this review was the increasing numbers of people suffering from dementia and the widespread view that often dementia is not diagnosed early enough and appropriate treatment is often not given. Such were the concerns that we decided to look at the application of the standards set out in the NSF through the 'lens of someone with dementia'. In the following chapters we have aimed to set out our findings against the steps in the 'journey of progression and care' that someone with dementia may travel. We have tried to describe that journey in the context of what the service users, carers and family members might experience and what they should expect.

Our review identified a number of examples of noteworthy practice as well as gaps that currently exist in services the context of an ageing population and the challenges that we will undoubtedly face over the coming years. The review contains a number of recommendations for what needs to happen next.

Key Findings

Overall we found that all those who participated in our review valued the focus that the NSF has brought to the need to think innovatively and outside 'of the box' when providing care and support to older people. However, the full implementation and consequent benefits of the NSF are still a long way off. Health and social care organisations and providers still have a lot to do in terms of refocusing their approach and agenda to one of prevention and empowerment.

When examining health promotion, well-being and prevention, which helps older people to stay well and keep living life the way they want to for longer, we found that greater investment is needed at a local level in health promotion, prevention and community services if older people are to be supported to live healthy and longer lives. This provides a dilemma for statutory agencies as the impact and benefits of such investment for them will not be immediate but longer term. They need to work more closely with the third sector to see how together they can put a cohesive approach to promotion and prevention in place. Our review highlighted a number of innovative and valuable services and support mechanisms, such as exercise and activity classes or shop and drop internet services such as the Food Solutions Project in Flintshire. However, there is variation in provision and in many areas there are still gaps. In particular more needs to be done to:

- coordinate and advertise activities locally;
- support those older people with substance misuse issues; and

- address the sexual health agenda for older people.

When we looked at how older people with dementia were supported to stay at home where possible rather than entering residential care, we made a number of findings. While there are indications that the quality of domiciliary services are improving, there is a continuing need to ensure that those who provide personal care to people who have dementia receive appropriate training. Service users and their families feel that often services are fragmented and do not provide support for their holistic needs. Services must understand the needs and preferences of those with dementia and their carers.

Some joint health and social care commissioning strategies are in place; however they are variable as is the quality of supporting protocols to ensure that they deliver co-ordinated and integrated packages of care. Overall, we found that communication and coordination across agencies and sectors needs to be improved. Third sector organisations told us that they felt that often their contribution is seen as *‘optional’* and they are not always asked what contribution they could make. There were concerns about the long term sustainability of services provided by third sector organisations that rely on short term grants and charitable funds. Statutory health and social care organisations should be realistic in terms of what they themselves can and cannot provide. They need to be open to the idea that many third sector organisations are better at providing certain services and work with them to ensure holistic and patient centred care.

As part of the review we examined a number of case files in a sample of community mental health teams (CMHTs) to assess what care was being provided by the team. A disappointing number of cases reviewed showed no evidence of a joint assessment or of the unified assessment process being followed; despite a requirement for the approach to be fully implemented by October 2006. We also found that sometimes different risk assessment processes are being used by health and social care staff.

People with dementia and their family carers do not feel sufficiently involved in the development of their care package, with 75% of those involved in our focus groups saying they had not been given any choice and 70% of participants saying that they had never accessed social care and hence relied on family members. On a positive note, some CMHTs have introduced dementia support worker posts which are proving to be extremely valuable. These posts provide support to people with dementia and their carers, helping them to maintain their independence, improving their sense of well-being and putting them in more control of their lives. They also assist people with dementia and their carers to identify their needs and access services.

Activities of Daily Living (ADL) skills training and cognitive behaviour therapy can promote independence in personal care tasks such as dressing, washing and feeding and help individuals manage their symptoms and behaviour. Disappointingly, none of the service users we spoke to had been involved in such training programmes. It is also clear that there is a shortage of community-based occupational and psychological therapy support. The principles of ADL should be used to develop activity plans that involve the individual and their carers in a variety of activities which ensure that the individual is integrated with their local community. Those we spoke to told us that they valued lunch clubs and the activities coordinated by third sector organisations, however sometimes activities were not suited to them and they felt that they just had to fit in.

The picture across Wales of the provision of full assessments or older people’s requirements for adaptive aids appears varied. Those we spoke to told us of delays in aids being provided and many said that such aids when provided were to support their physical needs rather than their memory needs. Telecare is a growing area where investment in technology can promote dignity and independence. It can be used as a preventative measure; for example, monitoring an individual's health or well-being, as well as responding to an immediate need such as a fall. There are examples of services such as this being piloted across Wales

The carers we spoke to told us that sometimes they felt forgotten and struggled to get statutory agencies to communicate and coordinate with them. They said that they found carers support groups, such as Alzheimer’s cafes where they can just drop in and have a chat with others in the same position, to be invaluable.

We also found that respite provision, out of hours support and weekend day care is inadequate and more needs to be done to achieve the aim of maintaining independence at home for as long as possible. Good quality respite care provided either in an individual’s own home, at a care home or at a community hospital facility, at a time to suit the carer, can aid people with dementia to live at home for longer. However, many of the carers we spoke to felt that the level of respite care they were offered was too little and often it could not be pre-arranged. In many cases we were told that respite was only offered when they had got to crisis point. Some carers told us that they had seen a decline in the general health and well-being of the individual they cared for following a respite stay.

Our review also looked at care in hospital. Whilst many of the findings do not have relevance to the focus of this review, planning for discharge back home or to an appropriate care setting was part of our work. People with dementia are estimated to account for over half of those people who remain in hospital unnecessarily. Intermediate care and rehabilitation beds, which could take patients who no longer need acute care, often explicitly exclude people with dementia. While there are some excellent examples of coordinated care and discharge planning, often there are gaps and shortcomings. Both health and social care professionals told us that decisions around continuing health care can be difficult and challenging. In particular, there are shortfalls in residential and nursing home capacity for those who have complex needs, which can lead to delays in transferring patients to the appropriate care setting. The further development of collaborative commissioning and planning between health and social care, coupled with an effort to unlock resources from traditional services, is the best way of tackling this challenge.

Planning for discharge should commence prior to any elective admission and immediately upon any emergency admission. However, we have noted many instances when discharge planning has been delayed due to late and uncoordinated care planning. This has wide implications for the individual as well as having a financial impact on the NHS. People should not stay in hospital longer than is necessary – it is not a place for well people and a longer than needed stay can also have detrimental effects upon an individual’s ability or confidence in returning to independent or supported living.

Overall, from our consultations with people with dementia and their carers and relatives it is clear that those with dementia do not always receive good person centred care. Quite often care is fragmented and reactive rather than proactive and responsive. There were however, signs of progress and improvement with most of the health and social care professionals recognising the need to change practice and work together. For example, as part of the Welsh Government’s Invest to Save Initiative, a £9 million support package was granted to the *‘Gwent Frailty Programme’* in September 2010. This programme is establishing an integrated model of care that is community based. The Gwent Frailty programme is just one example of innovative approaches being taken forward across Wales.

Our general review and inspection work, along with our statutory responsibilities for monitoring the application of the Mental Health Act and the Deprivation of Liberty Safeguards (the deprivation of liberty safeguards were introduced into the Mental Capacity Act 2005 by the Mental Health Act 2007) also provides information of interest to the Committee, some of which chime with the findings outlined above. Again one of the key issues we find in relation to older people in hospital is delays and frustrations around the discharge process, whether back home or to appropriate settings providing residential, nursing or rehabilitation care. There are a number of factors that are reported to us as causes:

- Insufficient residential and care settings in parts of Wales with the appropriate skills and facilities to meet the needs of individuals

- The complexity of the assessment processes that are required to be undertaken, and ensuring timely input from the various health and social service professionals to develop a holistic, multi-disciplinary understanding of an individual's needs

- Difficulty in reaching agreement on funding for packages of care

Carers also tell us of concerns about discharge processes, including a lack of information and sudden discharge, feeling they are not listened to regarding the patient's ability to manage at home or theirs to care for them, not having time to exercise choice and also a lack of information about funding arrangements and transparency about the decision making process. We have also found that the undertaking of carer's assessments is patchy.

We are also aware that there are insufficient specialist services for some older people with pre-existing mental disorders who then develop dementia. For example, patients who have been treated previously in low or medium secure hospitals: sometimes these individuals will find themselves moved on into residential or nursing care settings which have the skills and understanding necessary to manage dementia but not the complex needs of these individuals.

In contrast, we would also like to note that there are many examples of notable practice where staff from Health Boards and local community teams provide support, advice and training to staff in residential care settings.

We also feel that there is need for a shared understanding between the two sectors as to the expectations from residential care and health services of each other, and what can and cannot be provided, for example:

- Agreed plans of action should a resident in a care setting appear to be deteriorating – for example when and how to contact the crisis team of local mental health services

- what health staff will require to enable them to verify the identity of a resident with communication or mental capacity issues if they are taken for an outpatient procedure by care staff

- what support should be expected by health services from a care setting if a resident is admitted to hospital

Finally, we would like to highlight the need to ensure that decisions regarding individuals who do not have the capacity to make their own decisions are made following the legal framework of the 2005 Mental Capacity Act (MCA). We have found that whilst there are pockets of expertise in all organisations, the understanding and knowledge of the MCA amongst many health staff was still limited and sometimes led to uncertainty about what needed to be done. In this respect, The Committee might find it useful to hear evidence from statutory advocacy services (established under the MCA) about how well they are engaged in decision making processes. HIW and CSSIW have also been keen to promote public understanding of how individuals can take steps to ensure their views are known and make arrangements for their affairs to be managed as they wish, through the use of advanced decisions and lasting powers of attorney. We hope the Committee could highlight the rights and powers available to individuals as part of their findings.